Medical Advocacy: Speak Up!

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Today's Agenda

1) Welcome & Introductions
2) Finding the Right Doctor for YOU
3) Organizing Yourself
4) Making an Appointment
5) During the Appointment
6) After the Appointment
Finding the Right Doctor for YOU
Are you happy with your current doctor?

or
Questions to ask your doctor (or a potential new doctor):

• Are you comfortable working with someone who has a disability, and do you have experience working with people who have disabilities?

• Have you ever worked with someone who has my specific condition(s)?

• Does the doctor’s office or hospital have a patient advocate?
More Questions to ask

- Do you have exam rooms that can accommodate a large wheelchair and/or adjustable height medical exam tables?
- Is there someone who can assist with transfers? If not, does your office have a Hoyer Lift and are staff trained in how to use it?
- Is this a teaching hospital or facility? If so, will there be med students coming into my examination room? Do I have the right to accept or refuse those students?
- Have facility staff ever received disability sensitivity training?
Organizing Yourself for Medical Appointments
Helpful Tips to Keep Track of Appointments

- Don’t double-book yourself – always check your calendar (on your phone or personal calendar)

- Set alarm reminders or audio alerts for when it’s time to schedule or go to your next appointment
Create a list of questions and bring it to the appointment.
Bring important information about your medical condition(s) to every appointment

- Grab & Go binder
- Grab & Go bag
Make a “Grab & Go” Binder!

Include:

• Medical conditions / alerts
• Medical history
• Current medications
• Recent hospitalizations
• Allergies (to meds, latex, food, etc.)
• Prosthetics
• Durable Medical Equipment (DME) & Medical supplies
• Emergency numbers
• Names & numbers of other doctors you see
Make a “Grab & Go” Bag!

Include:

- List of medications
- Medication supply for 3 days (*refresh on a regular basis)
- Catheter supplies
- Disposable undergarments
- Toiletry/Personal care items (Chux, powder, …)
- Change of clothes
- Your healthcare passport or SDM agreement
- iPad for communication / communication device
- Recording device (or phone) – must get permission to record the doctor/nurse
- *Make sure everything is labeled with your name & phone number!
“Tell your staff or family member before the appointment that if the doctor or nurse speaks to them instead of you, they should direct the doctor or nurse to talk to YOU!”

- Tim Elliott, Self-advocate
Making an Appointment
When calling, remember to ask or say...

- How long will the appointment be?
- Is any procedure needed to be done at home before the appointment?
- Your needs (Transfer assistance, accessibility, etc.)
- Sedation requirements you may have
- Extra time you may need with the doctor if using a communication device
Call again 2–3 days **BEFORE** the appointment to remind them about your specific needs.
During the Appointment

Communicating Your Needs
Remember to bring:

- Your list of questions
- Grab & Go binder
- Grab & Go bag
At the start of the appointment,

• Discuss with the healthcare professionals your capacity to consent to care.

• If they have any concerns about this, you should have a conversation with them about it.

• A healthcare professional should not assume you need a healthcare proxy or someone else to make medical decisions for you.
Helpful Tips for a Smooth Doctor Visit

• Never assume that the doctor remembers everything about you!

• Start off every appointment by reviewing with your doctor the important parts of your medical history

• Have your binder out so the doctor can see it
If you are dealing with an unprofessional or inexperienced medical person...

- Take a breath before you respond
- Speak up for yourself! Show the person you know what you are talking about.
- Nicely remind the person to talk to YOU, not your caregiver
- Speak to someone in charge if there is a problem
Before you leave, ask the office staff to check with you before scheduling your next appointment to find out when you are available!
After the Appointment

Hopefully all went well, but if not...

How to Make a Formal Complaint
If you didn’t feel comfortable with the way you were treated or spoken to, call the doctor directly to talk about it.
Making a formal complaint

• Discuss your concerns with your staff or family member after the appointment and ask them for help (if needed) to make a complaint

• Contact the patient advocate to talk about your negative experience

• Find out if the hospital or medical practice has a quality assurance department – if so, contact them to express concerns
What if the doctor or nurse is not meeting my needs during the appointment?
Thank You!

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